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“Can I do that?” How advice impacts on reengagement for patients with heart failure

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Joyce’s words

Anne (researcher); “How do you know what you can do, how much you can do?”

• “It’s trial and error and you pay for it if you do too much, feeling tired, fatigued, you just know. I was told I needed to take it easy so you do. Everyone knows not to rush or lift heavy things to not put a strain on my heart”.

Anne (researcher); “So you have had to try things out for yourself, and you got advice?”

• “No I did it really, well and Jeff [husband] he was very clear what I should stop doing, he took over. They can’t be clear really I asked but they say just pace yourself and take it easy so I did- but really you have to try things out. Your mind stops you though; you’re scared to push yourself too much. You can’t see your heart so you have to guess and go on how you feel. Pushing you just a little at a time. No one really gives clear answers.”
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These influences can be summarised as the main influences on occupational performance and are identified below:

- Anxiety or fear of causing damage to the heart.
- Carer or family pressure to stop or modify activities which they view will damage the heart.
- General advice given by clinical team, and from publications aimed at this group of patients, and also those with heart disease and heart failure.
- The beliefs held by the individual about IDC M and what they need to do in order to “Guard their Heart”.  
- The avoidance of what the participant views as symptoms which are often “fatigue” and “breathlessness on exertion”.
Constructed Grounded Theory

Guarding the heart

Seeking Information
"what can I do?", "Can I do that?" General advice/individual advice. "no-one can tell you"

Reduced Occupational Performance
"I pace myself", "don't lift heavy weights", "don't stress the heart"

IDCM Work
Medical Work appointments, tests. Advice "pace yourself", reduce CHD risk factors in lifestyle.

Symptoms
Breathlessness and fatigue
"don't stress the heart", "damage"

Fear
Isolation
Loss
Anxiety
This core category “Guarding the Heart

The main factors which describe the occupational performance of people with IDCMI can be viewed as the following four concepts;

• **Seeking information**, the challenges that arise in the seeking and processing information about IDCMI. This information is then processed and interpreted and impacts on occupational performance and increasing adherence to IDCMI work.

• **Reduced occupational performance/participation**, reduced in the presence or **absence of symptoms in everyday life**.

Adopting IDCMI work; these are activities required for the medical management of the condition, ie, complying with medication, adopting a healthy lifestyle and pacing/avoiding activities.

**Symptoms**; which are provoked by activities and exercise and are viewed as damaging or ‘bad’ for the heart. Normal breathlessness and tiredness are interpreted as deterioration in the medical condition.
Influences on Occupational Performance.

- Anxiety
- Carer Pressure
- General Advice
- Reduced Occupational Performance
- Symptoms
- Beliefs